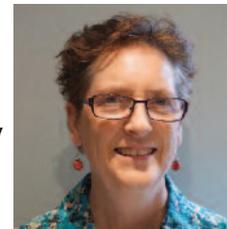


Diversity and inclusion in dementia research

Care interventions to support people with dementia from ethnic minorities must be evidence-based to receive funding, but what if research is lacking? **Lucy Whitman** investigates whether minority ethnic groups are being overlooked by the research community



A recent briefing paper by the British Psychological Society (2018) asserted that people from black, Asian and minority ethnic (BAME) communities “are all too often invisible within dementia research, either because they are not participants, or because their ethnicity is discounted.” If this is true, why is this, and what are the implications? I decided to investigate.

In 2013, an editorial in the *British Journal of General Practice*, written by Gill and Redwood, stated: “It has long been recognised that despite an often greater burden of disease, people from minority ethnic groups are under-represented in clinical and health research.”

In their powerful article, the authors argued that the research community needs to make a conscious effort to redress the imbalance, because “this often inadvertent exclusion has serious implications for medical science by limiting validity and generalisability, and for social justice by affecting the allocation of resources for services and research.”

Access to services

Moriarty *et al* in 2011 and the All-Party Parliamentary Group on Dementia (APPG) report in 2013, demonstrated that the needs of people with dementia from BAME communities were not fully met by mainstream services. Later commentators such as Truswell (2013), Clayton (2016) and the contributors to Botsford and Harrison Denning’s collection (2015) show how inequalities of access and outcomes have persisted.

The Race Against Dementia Campaign declared, in 2016, that “while there has been some improvement in the recognition of the impact of dementia on black, Asian and minority ethnic communities by policymakers in the past few years, there remains a lack of urgency regarding the scale and scope of this issue.”

As we know, in order to secure funding,

proposals for interventions to improve support for people with dementia and their families must be evidence-based. If people from BAME communities are still largely “invisible” within dementia research, this will perpetuate the unjust situation whereby, despite an apparently heightened risk of developing dementia, they are less likely to receive a timely diagnosis and appropriate support than their white counterparts.

Is exclusion inadvertent?

Alzheimer’s Research UK (2018) found that “people from a white ethnic background are more likely to consider getting involved in medical research for dementia than those from black, Asian and minority ethnic backgrounds (51% compared to 44%),” while Roche *et al* (2018) commented that “the barriers of recruiting BME in health research are not clearly understood but appear to be multifactorial and multilevel, and begin even before the actual initiation of the research study.”

In fact, there is some evidence that people from BAME groups are inadvertently being excluded from trials due to strict eligibility criteria. Cooper *et al* (2013) found that “participants in dementia intervention studies are, compared with those not included, more likely to be white, highly educated, younger and men. There is very preliminary evidence that people from non-white ethnic groups are less likely to be eligible for trials.”

In the same study it was pointed out that “people with dementia often have significant physical comorbidities or neuropsychiatric symptoms that may exclude participation,” and that “this has raised concerns about validity of findings and possible inequalities in access to research”. Significantly, this could also contribute to inequalities in health outcomes.

More recently, the risks of inadvertent bias were studied by Bayley *et al* (2018)

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who “compared the response rate to a randomised controlled trial (RCT) of a lifestyle intervention by CVD risk, ethnicity and level of deprivation” and concluded that “interventions for prevention of cardiovascular disease may not reach those most at risk. Hard to reach patient groups may require different recruitment strategies to maximise participation in future trials. Improvements in primary care ethnicity data recording is required to aid understanding of how successfully study samples represent the target population.”

Many commentators have pointed out the need for more personalised approaches, and more effective engagement with communities, in order to build the trusting relationships which are essential for research participation. Roche *et al* (2018) have successfully demonstrated that, when approached in a culturally competent way, black African and Caribbean elders are not only willing to engage with researchers, but also, “contrary to popular beliefs ... are willing to seek help for dementia from their GP.”

However, as Gill and Redwood pointed out, targeted approaches to minority groups are “more resource intensive and will require funding bodies to cover associated costs.”

How inclusive is research?

Jeraj and Butt commented in 2018 that we need to “encourage the research community to pay greater attention to race and ethnicity in research on dementia. The apparent lack of even inclusion of race and ethnicity as a category of data in several significant studies is concerning.”

The research community should acknowledge that people of different ethnicities may have different experiences of illness, treatment and care, including prevalence and incidence of certain conditions, impact of co-morbidities, access to services and access to participation in research. Findings that are valid for the majority white population might not always apply equally to people from BAME communities.

I wrote to the main research organisations to find out about their policies and practices on ethnic diversity. As well as asking about research specifically focused on the impact of dementia on people from BAME groups, I asked how inclusive generic dementia research is, whether people from different ethnicities are represented proportionately in clinical trials, whether the ethnicity of research subjects is routinely recorded, and what efforts are made to recruit participants from all sections of society. I also asked whether funders make any requirement that research should take into account the ethnicity and gender of research subjects.

I received some revealing replies. Some organisations responded thoughtfully and pointed me towards relevant research; some admitted they had only belatedly realised the importance of these issues; others claimed to have no relevant information.

Replies to questions

Alzheimer's Research UK and Alzheimer's Society both engaged enthusiastically with my enquiry and sent me useful information about recent and current research. Alzheimer's Society has recently published a statement on BAME communities and dementia research (2019) in which it acknowledges "we still have a lot to learn about the full impact of dementia in BAME communities and how best to offer appropriate support."

It encourages applications for research "exploring the experiences of different BAME communities in order to make appropriate cultural adaptations to interventions and services" or which "may shed light on the most effective preventative measures and the later stages of dementia, including end of life care for BAME groups."

Join Dementia Research (JDR) is the dedicated arm of the National Institute for Health Research tasked with recruiting members of the public to sign up to take part in research. "Until January 2019, ethnicity was an optional question for people signing up to the Join Dementia Research service," the organisation told me. "We realised that this meant we did

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not have visibility of the information needed to ensure that our volunteer population reflects the demographics of the UK population." JDR has recently changed its registration process to make ethnicity a question that all new participants must answer, "so that the people who participate in studies will better represent all the people that the research aims to benefit."

Brains for Dementia Research (BDR) provides researchers with post-mortem brain tissue donated by volunteers who sign up to a register. BDR told me that, with regards to recruitment, "this was a self-selecting cohort following advertising in GP surgeries, local hospitals, radio programmes etc. We did not seek participants from any particular ethnic group but neither did we exclude on the basis of ethnicity. We do routinely record participant's ethnicity but there were no conditions made in the grant as to whom we recruited – it was based purely on who came forward to volunteer their support."

Dementias Platform UK, funded by the Medical Research Council, brings together data from more than three million individuals, drawn from 47 long-term cohort studies of health, to make it easier for scientists to share knowledge and conduct joint research programmes. Its website encourages members of the public to volunteer to take part in studies and clinical trials and the introductory video states that "the DPUK portal brings [researchers'] data together enabling integrated data analysis" and "targeted studies". Yet their reply to my initial enquiry was "this isn't an area we can advise on at DPUK."

When I pressed them for an explanation of this response, they conceded that in fact "we can search our cohorts for ethnicity – most of DPUK's participating cohorts collect this variable within their sociodemographic data." I was also informed that one of their researchers "is hoping to run a research study across our

cohorts looking at ethnicity and dementia progression". So, in fact, this information is being recorded and in some cases analysed, yet my enquiry was not immediately recognised as pertinent to the work of the organisation.

Most surprising was the response I received from the UK Dementia Research Institute (DRI), which was set up in 2016. On its website it describes itself as a national institute which "brings together world-leading expertise in biomedical, care, public health and translational dementia research."

Among the aims of the DRI are to:

- "develop new approaches for delivering effective clinical trials to targeted patient groups"
- "develop and promote strategies for interventions that prevent the development or progression of dementia"
- "provide new insights and technology-based approaches to delivering more effective care and support to people with dementia and their carers."

These are all aims on which ethnicity might be expected to have a bearing. Yet the DRI enquiries team replied as follows: "As we are a basic research institute, we currently are not able to advise on the particular topics listed. If you contact Alzheimer's Society, they may have a better overview regarding the subject matter of dementia and ethnic groups." Given the ambitions listed on their website, I was rather taken aback by this reply. A further email received no response.

My informant at the Medical Research Council pointed me towards some interesting research, but told me: "As a research funder we do not record details of individual research participants. That being said each proposal should specify the number, sex, age range and state of health of the human participants. There is no 'specific requirement' to account for gender/ethnicity to receive funding; however, we expect applications to include sufficient methodological detail and where relevant to include consideration of the appropriate research participants."

The National Institute for Health Research (NIHR) exists to "improve the health and wealth of the nation through research". But the reply to my first enquiry to the NIHR Research Design Service in the London area was very brief. "Unfortunately, we would be the wrong organisation to provide this information."

Once again, I pressed my enquiry, and then received a reply from a different ➤

Research teams, ideally including people from varied backgrounds, need to be culturally competent, knowledgeable, open-minded and person-centred in their approach

► colleague: “For ethical and scientific reasons, funders must encourage the nation’s best researchers to conduct research in areas where health needs are greatest, including rural and semi-rural areas where many older people live. It also needs to engage and involve communities and health professionals who reflect the nation’s diverse population.”

I was then directed to the NIHR Dementia Researcher website, to look at the criteria for different funding programmes. All the funders have rigorous requirements, but none appears to require applicants to demonstrate that they will take account of possible ethnic or gender differences.

Is legislation needed?

These responses give rise to the question whether legislation is needed in the UK to ensure health research takes proper account of diversity. In the USA, since 1994, in order to receive federal funding for clinical trials, researchers are required to analyse their findings for validity in terms of “sex/gender, race, and/or ethnicity” (National Institutes of Health 2017).

In the UK, the NHS Health Research Authority’s updated policy framework (2018) lists the many laws which apply to the conduct of research, but there is no mention of equalities legislation. Roche *et al* (2018), who as we saw pointed out the need for more personalised approaches to BAME research, commented that regulations in the US had increased minority ethnic participation, adding that: “In the UK where there is no such legislation, the participation of ethnic minorities in trials is lagging far behind American trials.”

Would it not be possible for the major publicly funded research bodies to impose requirements on funding applications similar to those in the US? It appears that despite long-standing evidence that people from BAME communities are under-represented in health research – and the implications of this both for the validity of findings and for persistent inequalities in health outcomes – some of the major research bodies have no sense of urgency about rectifying this flaw. They may exhort researchers, in the words of my contact at NIHR, to “engage and involve communities and health professionals who reflect the nation’s diverse population,” but this is an aspiration, not a rigorous requirement, and as such it cannot be monitored or enforced.

Recent and current research

Despite the apparent lack of a strategic commitment to diversity and inclusion within the research establishment, there is nevertheless a dedicated band of researchers in the UK who have been working hard for many years to highlight the impact of dementia on people from minority communities. Recently published research is deepening our understanding of this impact and suggesting new lines of enquiry.

For example, rather than explaining “late presentation” to dementia services primarily by reference to cultural factors (lack of awareness, stigma), more recent research (e.g. Berwald *et al* 2016) has suggested additional reasons why people from BAME groups might not seek help in the early stages of dementia.

Roche *et al* (2018) and Hossain and Khan (2019) found evidence of changing attitudes and beliefs among black (African and Caribbean) and Bangladeshi communities respectively. Research published in 2019 by Cook *et al*, who investigated whether referrals to memory services in London reflect the ethnic diversity of the population, also suggested “a significant improvement in awareness of dementia and help seeking behaviour among BAME populations.”

A recent study by Tra My Pham *et al* (2018), who analysed a large number of primary care electronic health records, came up with new findings about dementia incidence and the likelihood of diagnosis in different ethnic groups. They found that “people from the black ethnic group had a higher incidence of dementia diagnosis and those from the Asian ethnic group had lower incidence compared with the white ethnic group.”

Furthermore, since black men were more likely to develop dementia, but less

likely to get a diagnosis, the researchers concluded that “the increased risk of dementia diagnosis reported in the black ethnic group might underestimate the higher risk of dementia in this group.”

As for the Asian, group (who it had previously been supposed would also have a heightened risk of developing dementia), it was “unclear whether the lower incidence of dementia diagnosis in the Asian ethnic group reflects lower community incidence or underdiagnosis.”

This reminds us that widely used cognitive tests are culturally biased and cannot be relied on to produce valid results for people of minority backgrounds, especially those who are not fluent in English (Blakemore *et al* 2018, Kok Pin Ng *et al* 2018.) While this issue remains unresolved, not only may some minority ethnic elders be deprived of a diagnosis which could open the door to treatment and support, but also estimates of incidence within particular groups may be incorrect.

The recent reports I have mentioned all stress that much more research is needed, both to investigate the new questions these studies have thrown up, and to underpin improved dementia care for people from BAME communities – and it appears that significant work in this area is currently in progress.

Alzheimer’s Society, for example, is funding work to develop diagnostic tests which are not culturally biased, as well as a large number of projects around the country exploring aspects of post-diagnostic care and support for people from different BAME communities. Another new project at Brighton & Sussex Medical School, jointly funded by NIHR and the Economic and Social Research Council, will look specifically at the question of “inequalities in service use and outcomes for people with dementia,” and will focus on “self-funders of care, older people of black Caribbean and South Asian heritage, and the older LGBTQ+ population.” It will also consider the “benefits and harms of earlier and later diagnosis of dementia.”

Finally, it is worth noting that there is at least one large and well-funded clinical research programme investigating “the mechanisms underlying heart disease, stroke, diabetes, obesity and other major medical problems” which clearly recognises the benefits of identifying ethnicity as a variable. This is the London Life Sciences Prospective Population Study (LOLIPOP) based in multi-ethnic west London and running since 2002, which has produced work of international importance. This shows that where there’s a will, there’s a way.

Not “ticking boxes”

Developing a more inclusive approach to research is not just a matter of ticking boxes. Researchers have to build trusting relationships with people from different communities, so they feel comfortable in agreeing to take part in research. Research teams, ideally including people from varied backgrounds, need to be culturally competent, knowledgeable and open-minded, and, as with all work involving people with dementia and their families, adopt a person-centred approach. Funding bodies should recognise that all this takes time to develop, and project budgets need to reflect this. ■

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